DECISION-MAKING IN MENTAL HEALTH REFERRAL: THE INFLUENCE OF GENETIC COUNSELOR EMOTION

by

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A thesis submitted to Johns Hopkins University in conformity with the requirements for the degree of Master of Science

Baltimore, MD
January 2020

Abstract

Genetic Counselors (GCs) receive training to screen for mental health concerns in their clients, yet little research has focused on the mental health referral practices of GCs. This study examines how the emotional state of GCs might influence their decision to refer clients to mental health services. The study design is based on the Appraisal Tendency Framework of decision-making, which hypothesizes that an individual's emotional state influences uncertain or ambiguous decisions (Lerner & Keltner, 2000). Practicing GCs (N=55) were induced to feel anger, sadness, or neutral emotion (as a control). They were then asked to read three case vignettes involving counseling scenarios they might see in clinic, assess whether they would refer the hypothetical client to mental health services, and how certain they were about this decision. GCs ranked the importance of their emotional state in referral decision-making. GC trait intolerance of uncertainty (IUS) was assessed as a potential effect modifier in the relationship between GC emotional state and decision certainty. Preliminary data suggest that negative emotion, specifically sadness, may increase certainty of referral decision-making, although this finding was not statistically significant ($P>0.05$). Genetic counselors in all emotion groups on average ranked their emotional state as low importance to their decision-making, suggesting they were not aware of any influence of sadness on referral. Additionally, sadness strongly modified the effect of certainty tolerance on decision certainty. This finding is not consistent with current research. This study provides preliminary evidence that emotion has an effect on genetic counselor decision-making. Implications for genetic counselor training and areas of future research are discussed.

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Preface

I would like to thank those who helped me throughout this project. I am so grateful to my advisor, Dr. William Klein, for his help and guidance throughout this process. I could not have accomplished my research goals without his expertise, thoughtfulness, and encouragement. I would also like to thank my thesis committee, Dr. Debra Roter, Dr. Rebecca Ferrer, Amy Turriff, and Julie Cohen, for their essential critiques, questions, and input. Thank you to Dr. Lori Erby for her mentorship while I learned how to be both a genetic counselor and a researcher. I would also like to acknowledge my classmates for helping me face the many challenges of graduate school. Thank you to my partner, Noah, for his endless patience while I prioritized thesis work, and for reminding me to never underestimate myself. I would like to thank my friends and family for their love and support throughout my graduate training. I could not have made it through this program without them. Many thanks to the National Institutes of Health for their investment in this project and their dedication to the genetic counseling field.

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Chapter 1: Background and Introduction

Mental Health in the United States

Mental illness can take many forms, ranging from mild to severe. According to the National Survey on Drug Use and Health (NSDUH), of the roughly 250 million adults living in the United States, almost one in five experienced some form of mental illness during the past year, yet only 43.1% of these individuals received mental health treatment (Substance Abuse and Mental Health Services Administration, 2017; "Total Population," 2018). About 16.2 million (6.7%) of NSDUH respondents had experienced at least one major depressive episode, and 37% of depressed individuals received no treatment for their symptoms (Substance Abuse and Mental Health Services Administration, 2017). Data from the National Comorbidity Survey (NCS) conducted by Harvard Medical School estimated nearly one third of U.S. adults experience an anxiety disorder throughout their lifetime (2007). When participants were surveyed about the severity of their anxiety within the past year, 22.8% had serious impairment, 33.7% had moderate impairment, and 43.5% experienced mild impairment (Kessler, Chiu, Demler, & Walters, 2005). In 2016, 44,965 individuals died from suicide (Xu, Murphy, Kochanek, Bastian, & Arias, 2018). That same year, 9.8 million adults from the NSDUH said they had thoughts about trying to kill themselves, and of that group, 1.3 million attempted suicide (Substance Abuse and Mental Health Services Administration, 2017). These data provide evidence that serious mental health concerns are prevalent in the United States.

Physical Health as a Risk Factor

Navigating medical diagnoses can generate new mental health problems or worsen existing ones. For example, approximately one third of cancer patients will experience significant distress during diagnosis and treatment of their disease (Derogatis, Morrow, & Fetting 1983; Carlson et al., 2004). A meta-analysis of 211 studies measuring depression in oncology patients

found that 8-24% of adult cancer patients experience depression—as compared to a 4% prevalence in the general US population—and 13% of adult cancer patients met the criteria for major depressive disorder (Krebber et al., 2014). In this same analysis, the pooled prevalence of depression peaked at 14% during treatment, and remained above the national average, at 9% in the first year after treatment, and 8% more than 1 year after treatment (Krebber et al., 2014). Individuals with a cancer diagnosis can also experience significant levels of anxiety. A 2004 study of 2,776 oncology patients showed that 30.3% met clinical criteria for anxiety (Carlson et al., 2004).

Significant mental health concerns also affect the population of individuals with a disability, including those who act as caretakers for family members with physical and intellectual disability. Having a physical disability can cause chronic stress, which may lead to mental health issues like depression. In a study of 727 self-identified disabled adults, 37% showed depressive symptomology and 11.3% met criteria for major depression, as compared to 12% and 6.2%, respectively, in the able-bodied comparison group (Turner & Beiser, 1990). One study of 294 Australian mothers of children with disabilities showed nearly half had clinically significant depression and anxiety, 30% showed psychological distress, and almost a quarter experienced suicidality (Gilson et al., 2018).

Increased medical risks and need for frequent exams and tests during pregnancy has also been linked to distress. The American Congress of Obstetricians and Gynecologists estimates between 14-23% of expectant mothers experience depressive symptoms during their pregnancy. In addition, there is growing evidence that women who give birth over the age of 35 experience higher rates of depression than younger mothers (Muraca & Joseph, 2014).

Clinical Guidelines for Referral

Several medical specialties have created guidelines for psychological assessment and referral that attempt to address the mental health needs of their patients. The Academy of

Psychosomatic Medicine created guidelines for referral in general medicine. These guidelines require that all medical staff receive training in recognizing situations that require psychiatric referral, with a focus on substance abuse, delirium, dementia, affective disorder, anxiety disorder, and suicidal ideation (Bronheim et al., 1998). Importantly, the authors highlight the ability for psychiatric concerns to be confounded in patients who have significant medical comorbidities (Bronheim et al., 1998). The nursing community has also examined clinical practice standards when it comes to mental health referral. Researchers have evaluated the best method for recognizing perinatal distress and incorporation of screening tools—such as the CFDT Mental Health Screening Tool—by nurses (Cole et al., 2016; Cole, 2017; Cole, Olkkola, Zarrin, Berger, & Moldenhauer, 2018; McCabe-Beane, Stasik-O'Brien, & Segre, 2018). Directing clinical practice in Oncology are the NCCN Distress Management Guidelines. The NCCN argues the importance of psychological referral guidelines since, "every single patient at every stage of disease, irrespective of the treatment, deals with issues that cause some level of distress" (National Comprehensive Cancer Network, 2003). The organization has gone as far as to include a screening tool in their distress management recommendations. Their Distress Thermometer and Problem List asks patients to rate their stress on a thermometer scaled from 0 (no distress) to 10 (extreme distress) and asks whether they are experiencing a series of family, emotional, physical, and practical problems (National Comprehensive Cancer Network, 2018). Publications that are more detailed like this provide a concrete protocol for clinicians to follow, and research has confirmed that implementation of these guidelines is achievable without significant provider burden (Fulcher & Gosselin-Acomb, 2007).

Genetic Counselors' Role in Mental Health

The oncology, disability, and prenatal populations may all see a genetic counselor as part of the diagnosis or treatment of their condition. As of 2018, the majority (46%) of genetic counselors see patients in the cancer setting, 32% in prenatal, 23% in pediatrics, and 23% in

general genetics, with many serving patients in multiple specialties (National Society of Genetic Counselors, 2018). Genetic conditions are often chronic and may affect the physical health of a whole family rather than just an individual. In addition, many people who seek genetic counseling may be healthy, but are 'at risk' based on a genetic susceptibility; this can take place after watching family members suffer from genetic conditions and acting as caregiver. Genetic counselors are trained in how to perform psychosocial assessments, and genetic counseling training programs are required to teach these skills for accreditation (Accreditation Council for Genetic Counseling, 2015). Therefore, genetic counselors are in a unique position to identify risk factors and find resources that may contribute to positive long-term mental health outcomes for their clients.

The ACGC Practice-Based Competencies for Genetic Counselors states clinicians should perform psychosocial assessments and make a follow-up plan to address a client's needs, which includes referral to mental health services (2015). The National Society of Genetic Counselors code of ethics similarly highlights this responsibility (2017). However, few studies evaluate how this standard is carried out by genetic counselors in clinical practice, and there are currently no clinical practice guidelines for mental health referrals by genetic counselors. In a 2018 study that interviewed 28 genetic counselors about their referral practices, the majority agreed that genetic counselors can provide short-term support but should refer out for more significant problems that require long-term support. The same study cited multiple reasons why individuals were identified for a referral, including distress related to being at-risk for or having a genetic diagnosis, difficulty with medical decision-making, and life circumstances unrelated to the genetic counseling session (Cunningham, Morreale & Trepanier, 2018).

Factors of Mental Health Referral

Accurate assessment and referral of patients in need of mental health services requires adequate training, but also individual clinical judgment skills that may vary between clinicians.

Studies evaluating clinicians' ability to identify psychological distress in the healthcare setting have yielded mixed results. There is evidence that medical providers underdiagnose (Anderson & Harthorn, 1989) or over-diagnose (Hilton, Bajaj, Hagger, Taha, & Warner, 2008; Sollner et al., 2001) mental health concerns, depending on the circumstances of the evaluation. In addition, one study showed PCP's accuracy of diagnosis was greater for organic disorders (e.g. dementia and brain injury), rather than affective, anxiety, somatic, and personality disorders (Anderson & Harthorn, 1989). This suggests that clinicians are not always sensitive to distinguishing between levels of distress in their patients, especially when symptoms are related to psychiatric rather than neurocognitive disorders.

Several factors affect whether medical providers decide to treat a mental health concern themselves, versus referring to a specialist. One study of factors influencing PCP's referral decisions is consistent with previous literature, citing limitations based on structural issues within the healthcare system (e.g. limited time to discuss a patient's mental health during an appointment); however, a larger influence was the clinician's familiarity with treating depression and perception of the complexity of this mental health issue (Anthony et al., 2010). Similarly, a 2018 study revealed that PCPs with low confidence in treating mental health concerns were more likely to refer patients to specialists; however, lack of training in behavioral health did not predict referral practices (Peterson, Pidano, & Honigfeld, 2018).

In addition to cognitive skills, clinician emotion can play a role in clinical decision-making. Models of clinical decision-making do not always explicitly address emotion or consider it essential to the decision-making process. More recent studies, however, have discussed its importance. A systematic review of the literature (N=23 papers) highlights how emotion can lead to both appropriate and inappropriate clinical decision-making. While 'gut feelings' were described in multiple studies as important assessment tools, it was also essential for providers to have emotional awareness in order to appropriately weigh their feelings in a decision (Kozlowski, Hutchinson, Hurley, Rowley, & Sutherland, 2017). This is consistent with literature on emotion

and decision-making in general, where emotion can lead to both advantageous and disadvantageous decisions (Lerner, Li, Valdesolo, & Kassam, 2015).

In genetic counseling, there is little research regarding what factors act as catalysts or barriers to referral. A study by Cunningham and colleagues identified domains to referral barriers, including patient characteristics (e.g. patient not receptive or does not see benefit to referral), logistics of the GC work environment (e.g. difficulty identifying mental health providers or logistical problems), and lack of accessibility to appropriate services (e.g. insurance or availability of providers) (Cunningham et al., 2018). The study also cited multiple scenarios that prompted referrals, including patient distress about having a genetic diagnosis or being genetically at-risk, difficulty with decision-making, or reasons unrelated to the session (e.g. personal history of mental illness or lack of social support) (Cunningham et al., 2018). Their research did not focus on genetic counselor characteristics, and no research to date evaluates the relationship between genetic counselor emotion and referral decision-making.

The Appraisal Tendency Framework as a Conceptual Model for Mental Health Referral

Genetic counselors are expected to make objective judgments about the psychological needs of their clients, but inevitably, emotional aspects will influence their decision-making. To account for the effects of emotion on GC decision-making for mental health referrals, the proposed study is informed by the Appraisal Tendency Framework (ATF) for decision-making. This model is grounded in the idea that emotion is not a separate variable that influences an otherwise rational decision-making task but is an integral part of how we make judgments. Decisions can be influenced by *integral emotions* (those directly related to the decision) and *incidental emotions* (those experienced at the time of the decision but elicited by factors not directly related to the decision) (Loewenstein & Lerner, 2003).

The ATF proposes six appraisal dimensions and an appraisal theme for each emotion (outlined in Table 1), and these domains inform the content of our decisions in unique scenarios (Ferrer, Klein, Lerner, Reyna, & Keltner, 2016, p. 108; Lerner & Keltner, 2000). All of these dimensions of appraisal can influence the perceived risk and reward from making a decision, and whether a decision is processed heuristically (simple and shallow) or systematically (complex and deep) (Han, Lerner, & Keltner, 2007).

The current study examines the role of induced incidental emotions in GC decision-making that might arise from situational factors (unrelated to the mental health referral decision) such as interactions with previous clients, the GC work environment, or a countertransference reaction to the patient. Further, how genetic counselors' clinical decision-making may be influenced by the certainty dimension of incidental emotions is explored.

Appraisal Dimension	**Sadness**	**Anger**
Valence	negative	negative
Certainty	**medium**	**high**
Personal control	low	high
Situational responsibility	high	high
Attentional activity	low	medium
Anticipated effort	low	medium
Appraisal Theme	Feeling irrevocable loss	Feeling slighted or demeaned

Table 1. Dimensions of decisional appraisal in sadness and anger emotional states (adapted from Ferrer et al., 2016, p. 106).

Intolerance of Uncertainty

Decisional uncertainty can arise for different reasons, including aspects of the decision situation, and traits of the decision-maker. Intolerance of uncertainty (IUS) describes the

"cognitive, emotional, and behavioral reactions to situational uncertainty" and is a trait of an individual (Rosen, Ivanova, & Knauper, 2013). In general, those with high trait worry and anxiety tend to have greater intolerance for uncertainty. Those with high IUS tend to have a more negative emotional, cognitive, and behavior reaction to decision-making, more anxiety over an uncertain outcome, interpret ambiguous information as threatening, and look to seek more information in order to make a decision (Einstein, 2014). This results in avoidance of decision-making, impaired problem-solving, and interpretation of ambiguous information as threatening (Hillen 2017 conceptual analysis of the literature). Research has shown that high IUS affects decision-making despite the skill level or training of the decision-maker (Dugas, Letarte, Freeston, & Ladouceur, 1995). Individuals with high IUS typically feel less certain when making a decision. In this study, we explore how individual personality traits like intolerance for uncertainty might modify the relationship between genetic counselor incidental emotion and certainty of their decision-making.

This research examines the mental health referral practices of genetic counselors (GCs), and how these practices might be influenced by an induced, incidental emotional state. To this end, an online survey to GCs was distributed through the National Society of Genetic Counselors (NSGC) listserv and at the NSGC annual conference. The **primary hypothesis** of the study was that GC emotional state would influence mental health referral decision certainty consistent with the appraisal tendency framework (ATF) of decision-making (Lerner & Keltner, 2000). GCs induced to feel sad or angry were predicted to report feeling more certain about their referral decision for hypothetical case vignettes compared to referral decisions of a control group. Based on the patterns outlined in the ATF, the effects from anger on certainty were expected to be greater than the effects from sadness. Two **exploratory hypotheses** were also examined: first that GCs would not be aware of the influence of an induced emotional state on referral decision-making. Second, that the effect of emotional state on decision-making would be modified by GC

trait measures of intolerance for uncertainty. Since sadness generally elicits more uncertainty than anger, we expect a greater interaction with IUS to take place in the sadness group.

Chapter 2: Methods

IRB Approval

This study was approved by the Institutional Review Board of the Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland on June 20, 2019.

Validation of Study Measures and Scenarios

Genetic counselors were contacted directly by the study team to request participation in a validation of the study survey, with a goal of recruiting N=5 participants. Participants were asked to assess vignette clarity and inclusion of sufficient detail for clinical assessment. They were also invited to provide feedback about clarity of the remainder of the survey, and time taken to complete the survey.

Study Population

Survey participants were eligible if they were board certified genetic counselors with a minimum 1 year of experience who work directly with patients and subscribe to the NSGC email listserv. There were not eligibility restrictions based on demographics such as participant age, race, or gender. Recruitment took place through the NSGC Student Survey Research Program, which sends out a weekly email blast to help recruit genetic counselors to participate in student research projects. A short description of the study along with a link to the Qualtrics survey was provided in the e-mail blast for genetic counselors to access the consent form and study survey. Additional in-person recruitment took place at the NSGC Annual Conference from November 5th through November 8th, 2019.

Informed Consent

The first page of the survey included the consent document, and participants provided consent by initiating the survey. Inclusion criteria were outlined in the recruitment email and consent form. Participants were informed that their survey responses would not be linked to their identity, and personal identifiers would not be collected as part of the survey. Participants had the option to receive a $10 Amazon gift card in exchange for their time. They also had the option to receive a summary of study results, once they are available. Contact information to receive their gift card and/or summary of study results was collected separately from the study survey to ensure protection of privacy.

Statistical Software

All data analysis was performed using Stata/IC 15.1 statistical software.

Response Exclusion

Responses were discarded if participants did not meet inclusion criteria outlined in the informed consent, if participants did not complete the emotion induction essay, or if they did not answer all survey items required to evaluate our study aims.

Procedures

The study survey was distributed using the Qualtrics online platform. Participants were randomized to one of three emotion induction study groups. All participants completed a 39-item questionnaire. To avoid a testing effect, a randomized subset of 25% of participants was asked to assess their current emotional state. Questions consisted of a combination of validated scales, and

questions designed specifically for this study. The survey was estimated to take approximately 20 minutes to complete based on survey validation.

Emotion Induction

Study participants were randomized to one of three emotion induction groups: anger, sadness, and a neutral emotion control. The anger and sadness groups were asked to write for 5 minutes about 3-5 situations that currently make them angry (anger group) or sad (sadness group), then write in more detail about one of these situations in a way that would make someone else feel angry or sad just reading about it. The neutral control group was asked to describe 3-5 rooms in their house, then write in more detail about one of these rooms in a way that someone reading the essay could imagine themselves in the room (Strack, Schwartz, & Gschneidinger, 1985).

Case Vignettes

Participants were then asked to read three case vignettes about patients similar to what they might encounter in clinic. The vignettes described the mother of a 9 y.o. boy with Charcot-Marie-Tooth hereditary neuropathy (CMT), a woman receiving genetic testing after having breast cancer in her 60's (breast cancer), and a man in his 20's being followed for Marfan syndrome (Marfan syndrome). The vignettes were designed to represent realistic genetic counseling patients who were experiencing signs of anxiety or depressive symptoms based on American Psychiatric Association DSM-V severity measures (PROMIS Health Organization, 2012; Spitzer, Kroenke, & Williams, 1999). The goal was to describe a clinical situation where the patient is experiencing a moderate level psychological distress. Each case was written to be intentionally ambiguous, such that either to refer or not refer each client was clinically reasonable.

Intolerance of uncertainty

Participants were asked to complete the intolerance for uncertainty scale (IUS-12) (Carleton, Norton & Asmundson, 2007), a 12-item measure of worry about future events. The scale included items such as, "Unforeseen events upset me greatly" and, "When it's time to act, uncertainty paralyses me". This variable was measured in order to determine whether respondents' level of intolerance to uncertainty modifies the effect of GC emotional state on decision-making certainty.

Clinical Assessment

After each vignette, participants were asked a series of questions to assess the mental health status of the hypothetical patient or patient's parent. They were asked whether they would schedule follow up with the patient or parent to evaluate his or her mental health status further. Then they were asked whether they would refer the client to mental health services (yes/no), and how certain they felt about their decision (7-point Likert scale from 1 = 'not at all certain' to 7 = 'extremely certain').

Demographics and Clinical Practice

Counselors were asked for demographic information, years of clinical experience, and specialty. They were asked about their current mental health assessment and referral practices, and whether it is within their scope of practice to make referrals to mental health services. Participants reported whether they had clinical supervision included in their masters' program, and if they participate in clinical supervision currently. Information about the clinic where they

currently work was gathered, including whether their clinic has a system in place to make mental health referrals and a full-time mental health provider on staff. This information was gathered to assess the representativeness of the sample to the field as a whole. Clinical training and level of experience of respondents was collected to better interpret implications of study findings for training

Statistical Analysis

Sample Size Calculations

The recruitment goal for this study was 375 GCs. This number was estimated based on previous literature that uses emotion induction methods. According to a meta-analysis by Lench and colleagues, the essay writing mood induction showed an effect size of g=0.26 for sadness vs. neutral control (95% CI [0.19, 0.33], N=95 studies) and g=0.36 for anger vs. neutral control (95% CI [0.20, 0.52], N=31 studies) (Lench, Flores, & Bench, 2011). A power analysis revealed that a sample size of 375 would be needed for an effect size of 0.36 and a power of 0.8. The study team expected this study's effect size could be larger because this meta-analysis included studies where the effect size of certain moods was expected to be small based on the outcome being studied. In addition, several studies in this meta-analysis used college students participating for class credit, and we expected that GCs would be more engaged study participants.

Evaluation of Emotion induction method

Positive and Negative Affect Schedule (PANAS) scores were analyzed to confirm that the emotion induction procedure had the desired effect on respondent emotional state. Due to the potential confounding effect on emotional state from filling out the PANAS scale, only twenty-five percent of participants from each emotion induction group were randomized to complete it.

Participants were asked to indicate, from 1=very slightly to 5=extremely, to what extent they currently felt different positive and negative emotions. The schedule included a list of 22 emotions, including 'sad' and 'angry'. Mean scores for positive affect, negative affect, sadness, and anger were calculated for each randomized group. Successful effect from the emotion induction would result in the sadness and anger groups having higher negative affect scores on average.

Referral Decision

The decision to refer or not refer was tallied for each group, and in total. In order to confirm vignettes were written in such a way that it was equally reasonable to refer or not refer each client, we assessed the ratio of refer to not refer. Vignettes that were not close to a 50/50 ratio were discarded.

Decision Certainty Outcome

Regression analysis was used to evaluate whether the emotional state of GCs affected their decision to refer clients to mental health services. Responses to the question, "Referring to the [mental health referral decision], how certain are you of this answer?" were compared for each vignette. This question will be referred to as the 'certainty question'. We also examined how the average response to the certainty question summed across vignettes differed between each emotion induction group. Before doing so we assessed whether responses to the three case vignettes were correlated, and if so, whether responses could be summed across vignettes to increase reliability. Regression analysis was used to evaluate whether induced emotional state had an effect on referral decision certainty.

Associations between PANAS score and referral decision as well as certainty of decision were evaluated. PANAS scores for positive affect, negative affect, sadness, and anger were separately analyzed. The correlation between PANAS score and certainty of decision, as well as PANAS score and refer/not refer was performed using Spearman's rho. ANOVA was performed to evaluate variation in referral outcomes by PANAS scores.

Awareness of emotional state on decision-making

Ranking of the nine referral decision factors was tabulated and evaluated to determine most important and least important factors. The average rank of 'my emotional state' was calculated for each vignette. Analysis of variance was performed to determine variation in the ranking of 'my emotional state' across the three randomized groups.

Intolerance of uncertainty as modifier of GC emotional state on certainty of referral decision

Mean IUS scores were compared between groups to confirm if randomization was successful. Regression analysis that included a group assignment by IUS score interaction term was used to evaluate whether there was a modifying effect of IUS on the relationship between emotion group assignment and the decision certainty variable. In addition, effects of high vs low IUS score on decision certainty were analyzed separately for each emotion group. Regression analysis of IUS scores and decision certainty were run for each randomized group. IUS scores 1SD above the mean and 1SD below the mean were input into our regression equation to estimate certainty outcome for these IUS values. These values were graphed to facilitate between-group comparison.

Chapter 3: Results

Validation of Study Measures and Scenarios

Five practicing GCs and three GC students were contacted requesting participation in survey validation. A total of N=4 GCs and N=1 GC student assisted in the validation of the study scenarios by providing feedback on the clarity and accuracy of vignettes, and clarity of survey questions. Multiple participants requested that it be made more explicit whether contents of essay responses would be kept confidential, and edits were made to the consent form and essay instructions. Both a survey validation participant and a study participant (as an optional comment) said that they sometimes discuss mental health with patients, without making a formal referral. To address this, a related question was added to the study survey in an amendment approved on October 25, 2019.

Study survey

Response Exclusion

A total of N=125 responses were collected as of November 16, 2019. One participant was a laboratory GC without patient contact and deemed ineligible. A total of N=68 responses were incomplete and discarded. Five of the incomplete responses had a completed emotion induction essay with the remainder of the survey left blank. For N=63 responses, the participant read the consent, and stopped taking the survey after viewing the emotion induction essay question. This suggests that the essay-writing exercise was a major barrier to participation. As of November 16, 2019, N=55 survey responses (44%) met inclusion criteria for analysis.

Participant Demographics and Clinical Practice

Participants were predominantly non-Hispanic white (90.7%), young (M=29.5±5.9 years), and female (92.7%) (see Table 2). This corresponds with the demographics of genetic

counselors nationally. Study respondents had an average of 4.6 years of clinical experience (SD 5.19; range 1-30 years) (see Table 3). Most respondents worked in cancer genetics (47.3%) and pediatrics (30.9%), with 25.4% working in more than one specialty (see table 3). Other participant-reported specialties not listed in the survey included preconception (N=2) and fertility/PGT-A (N=1).

Table 2. Study participant self-reported demographics

Age (N=55)		**(M±SD)** 29.5 ± 5.9
Biological sex (N=55)	Male Female Other Choose not to specify	**N (%)** 3 (5.5) 51 (92.7) 0 (0) 1 (1.8)
Self-identified race/ethnicity (N=54)	White Black/African American Native American/Alaska Native Asian/Pacific Islander Hispanic/Latino Other More than one race/ethnicity	**N (%)** 49 (90.7) 1 (1.9) 0 (0) 4 (7.4) 0 (0) 0 (0) 1 (1.9)

Participants reported seeing an average of 10.7 patients per week (SD 4.6; range 1-25), which can be extrapolated to estimate an average of 550 patients per year. Participants most frequently reported making between 1 and 5 mental health referrals per year (N=30; 54.6%). The second most common referral practice was making no referrals annually (N=15; 27.3%). None of the respondents reported making >15 referrals per year (see table 3). These referral rates are slightly lower than those reported in a study of GC referral practices by Cunningham and colleagues; however, GCs in that study were required to have made at least one mental health referral in the last year for study participation (Cunningham et al., 2018).

A subset of participants reported frequency of discussing seeking mental health support with clients, without making a formal referral (N=13). Significantly, all these participants reported having at least one mental health support discussion in the past year. The majority reported discussing mental health support with patients 1-5 times (N=4; 30.8%) or 6-10 times (N=5; 38.5%) per year. A small number of participants (N=4) discussed mental health support with clients 11-15 or >15 times in the past year (see table 3). To our knowledge, previous research has not collected data regarding GC mental health assessment practices, and we cannot say whether our findings are consistent with national averages.

Table 3. Study participant self-reported clinical practice

Specialty (N=55)		**N(%)**
	Prenatal	12 (21.8)
	Cancer	26 (47.3)
	Pediatrics	17 (30.9)
	Research	7 (12.7)
	Laboratory	1 (1.8)
	Other	9 (16.4)
	More than one specialty	14 (25.4)
Years of clinical practice (N=55)		**(M±SD)**
		4.6 ± 5.2
Patients per Week (N=55)		**(M±SD)**
		10.4 ± 4.6
Mental health referrals in last year (N=55)		**N(%)**
	None	15 (27.3)
	1-5	30 (54.6)
	6-10	6 (10.9)
	11-15	4 (7.3)
	>15	0 (0)
Mental health support discussions in last year (N=13)		**N(%)**
	None	0 (0)
	1-5	4 (30.8)
	6-10	5 (38.5)
	11-15	2 (15.4)
	>15	2 (15.4)
		Yes (%)
Screen for mental health concerns? (N=55)		23 (41.8)
If yes, use screening tool? (N=23)		4 (17.4)
Referral system in my clinic? (N=55)		25 (45.5)
Mental health specialist in my clinic? (N=55)		20 (36.4)
Within scope of practice to refer? (N=55)		47 (85.5)
Clinical supervision in grad school (N=55)		32 (58.2)
Clinical supervision professionally (N=55)	One-one-one	25 (45.5)
	Peer	14 (25.5)
	None	24 (43.6)

Emotion Induction

Twenty-five percent of each emotion induction group was randomized to complete the PANAS scale (N=14). Mean scores for each group showed the expected trend, with the sadness group scoring most sad, anger group most angry, and anger/sadness groups having higher negative affect scores than the neutral control group (see table 4). The main effect of condition in ANOVAs conducted on the affect variables was significant for sadness ($p = .02$) but not for anger ($p = .08$), summed positive affect ($p = .68$), nor summed negative affect ($p = .75$).

Group	**Sad Score (scale 1-5)**	**Angry Score (scale 1-5)**	**Positive Affect (scale 10-50)**	**Negative Affect (scale 12-60)**
Neutral (N=5)	1.4 ± 0.55	1.4 ± 0.89	24.6 ± 8.76	14.8 ± 4.76
Sadness (N=4)	4.0 ± 0.82	1.0 ± 0.0	22 ± 7.62	17.3 ± 6.34
Anger (N=5)	2.2 ± 1.64	2.8 ± 1.64	20.6 ± 4.72	17.2 ± 5.89
Total (N=14)	2.43 ± 1.50	1.79 ± 1.31	22.43 ± 6.86	16.36 ± 5.33

Table 4. Mean PANAS scores by randomized emotion group.

Referral Decision and Certainty of Decision-Making

Decision to refer or not refer was tallied for each group, and in total. For the CMT and breast cancer vignettes, roughly half of participants chose to refer the hypothetical client (see table 5). For the Marfan syndrome vignette, most participants in all groups chose to refer the hypothetical client (90.9%), suggesting that a characteristic of the vignette skewed responses

towards choosing referral. Therefore, Marfan syndrome was excluded from analysis of referral decision and certainty of decision.

Correlation analysis was performed to determine if the responses to the 'certainty' question were correlated between vignettes. Most inter-vignette correlations were significant (CMT and Marfan syndrome r=0.33, p=0.02; breast cancer and Marfan syndrome r=0.40, p=0.003), and only the correlation between the CMT and breast cancer vignettes was not significant (r= 0.23, p=0.09), but was likely underpowered.

The relationship between decision-certainty and induced emotional state was evaluated for the CMT and breast cancer vignettes, combined. There were no significant main effects of induced emotional state on decision certainty (anger β=0.03, p=0.94; sadness β=0.46, p=0.21).

	Neutral (N=22)	**Sadness (N=16)**	**Anger (N=17)**	**All (N=55)**
CMT *% Refer (N)* *Certainty (mean±SD)*	36.4 (8) 4.0 ± 1.2	50 (8) 4.75 ± 1.48	41.2 (7) 4.18 ± 1.67	41.8 (23) 4.27 ± 1.45
Breast Cancer *% Refer (N)* *Certainty (mean±SD)*	54.5 (12) 4.59 ± 1.05	50 (8) 4.75 ± 1.57	52.9 (9) 4.47 ± 1.46	52.7 (29) 4.60 ± 1.33
Marfan Syndrome *% Refer (N)* *Certainty (mean±SD)*	90.9 (20) 5.09 ± 1.41	87.5 (14) 4.88 ± 1.78	94.1 (16) 5.35 ± 1.06	90.9 (50) 5.11 ± 1.42

Table 5. Proportion of participants who decided to refer, and average certainty of decision (on Likert scale 1-7).

Looking at the means of the certainty response across vignettes, the greatest effect of the emotion induction can be seen in the CMT case. This is probably not surprising as CMT was the first vignette to be read immediately after the emotion induction procedure. Analysis of the effect of emotional state on the decision certainty outcome was performed for CMT alone. Regression

analysis revealed no significant main effect of anger or sadness on decision certainty (anger β=0.18, p=0.71; sadness β=0.75, p=0.12). We then evaluated the effect of emotional state in breast cancer alone. Regression analysis for breast cancer showed no statistically significant main effect of group on decision certainty (anger β =-0.12, p=0.78; sadness β=0.16 p=0.72). Analysis was performed to evaluate referral decision-making based on PANAS scores (regardless of emotion induction group) on those that completed the PANAS scale (N=14). Spearman's correlation showed no statistically significant correlation between whether respondents decided to refer/not refer the CMT hypothetical client and their PANAS scores for angry, summed positive affect, and summed negative affect (p>0.05). Sad scores and decision to refer/not refer for CMT were statistically significantly correlated (ρ=0.61, p=0.02). None of the abovementioned PANAS scores were statistically significantly correlated with the referral decision for the breast cancer vignette (p>0.05).

T-tests were performed to compare mean PANAS scores for the refer and not refer groups. For CMT, there was no statistically significant difference between those who chose to refer vs those who chose not to refer and their mean PANAS scores for anger (t=-0.03, p=0.98), positive affect (t=1.88, p=0.09), and negative affect (t=-1.57, p=0.14). There was a significant difference in mean sad scores between the refer and not refer groups (t=-2.6, p=0.02), with more choosing to refer as sadness scores increased. For breast cancer, none of the PANAS scores were statistically significantly different between the refer and not refer groups (P>0.05).

Spearman's correlation was also performed to determine correlation between the mean referral decision certainty response for CMT and breast cancer, and the sad, angry, positive affect and negative affect PANAS scores. None of these items were statistically significantly correlated with certainty of the referral decision (p>0.05).

Factors influencing referral decision

Overall, genetic counselors gave low importance to their emotional state as a factor of mental health referral decision-making. This held true for all three vignettes (see Figure 1). On a scale of 1=most important to 9=least important, the decision-factor 'my emotional state' was ranked highest for CMT (M=7.95, SD range=2-9), second highest for breast cancer (M=8.20, range=4-9), and lowest for Marfan syndrome (M=8.31, range=5-9). Interestingly, the range of responses was greatest for the CMT vignette. Analysis of variance showed no statistically significant variation in the ranking of 'my emotional state' across the three randomized groups (p=0.79). This was also reflected in linear regression analysis, which showed anger and sadness groups did not significantly vary in their responses from the neutral control (p=0.67 and p=0.77, respectively).

Individuals who reported having supervision as part of their master's degree program ranked 'my emotional state' higher, on average, than those who did not, although a t-test of the difference in means was not statistically significant (student supervision M=7.72±1.46; no student supervision M=8.26±1.36; p=0.54). Average ranking of 'my emotional state' was also not significantly different between participants who have either peer or one-on-one supervision as part of their professional career, as compared to those with no supervision (supervision M=7.84±1.51; no supervision M=8.08±1.35; p=0.54).

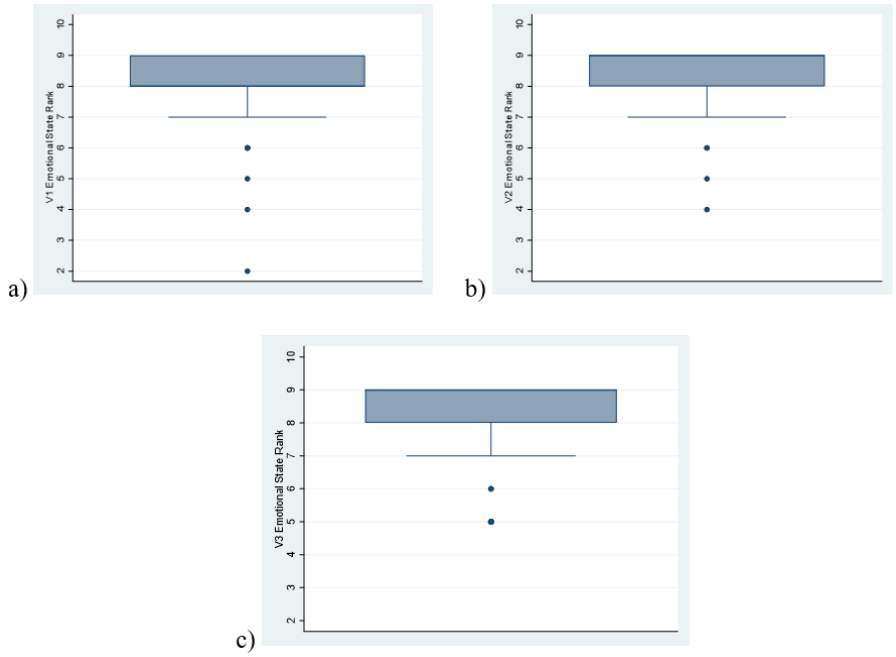


Figure 1. Ranking of 'my emotional state' as a factor of mental health referral decision (out of list of 9 referral factors, 1=most important and 9=least important) for a) CMT, b) breast cancer, and c) Marfan syndrome vignettes.

The two highest ranking referral decision factors for CMT and breast cancer were 'patient's/mother's distress level' and 'patient's/mother's reaction to genetic diagnosis' (see table 6). For Marfan syndrome, 'patient's social support' was most frequently ranked most important (N=26), followed by 'patient's distress level' (N=10) and 'patient's engagement in session' (N=9).

Vignette	Most important	2nd most important	Least important
CMT (N=55)	Mother's distress level N= 26 (47%)	Mother's reaction to genetic diagnosis N=14 (25.5%)	My emotional state N=25 (45.5%)
Breast Cancer (N=55)	Patient distress level N=23 (41.8%)	Patient's reaction to genetic diagnosis N=13 (23.6%)	My emotional state N=30 (54.6%)
Marfan Syndrome (N=55)	Patient's social support N=26 (47.3%)	Patient's distress level N=10 (18.2%)	My emotional state N=38 (69.1%)

Table 6. Importance of referral decision factors out of list of 9 items. Columns outline items most frequently ranked 'most important', second-most frequently ranked 'most important', and most frequently ranked 'least important'.

Intolerance of Uncertainty as Effect Modifier

Preliminary analysis was based on a small sample size, as data collection was stopped due to time constraints. Mean IUS scores for the three emotion induction groups were similar (Neutral=30.6±10.2; Anger=30.9±7.6; sadness=31±9.96), providing assurance that randomization was successful. Regression analysis showed no statistically significant main effect of IUS score on certainty (β= -0.035, p=0.12, 95% CI [-0.08, 0.009]). There was, however, a statistically significant interaction between IUS and assignment to the sadness group (β=0.097, p=0.008, 95%CI [0.027, 0.167]). There was no statistically significant interaction between IUS and anger group assignment (β=0.014, p=0.73, 95%CI [-0.068, 0.096]).

The certainty outcome for IUS scores 1SD below the mean and 1SD above the mean was calculated to look for patterns based on self-reported intolerance of uncertainty. Regression analysis of IUS scores and decision certainty were run for each emotion group. IUS scores 1SD above the mean and 1SD below the mean were input into our regression equation to estimate certainty outcome for these IUS values (Aiken & West, 1991). These calculations—represented in Figure 2—show different effects of decision certainty by emotion group. Whereas decision certainty for those with low and high IUS scores was similar across the anger and neutral groups, the sadness group differed. Sadness predicted high decision-certainty for individuals with low tolerance for uncertainty (high IUS score), and low decision-certainty for individuals with high tolerance for uncertainty (low IUS score). These findings differed from the expected main effect from IUS on decision certainty where high IUS individuals are less certain in their decision-making, and low IUS individuals are more certain. The sadness group showed the opposite pattern (see Figure 2).

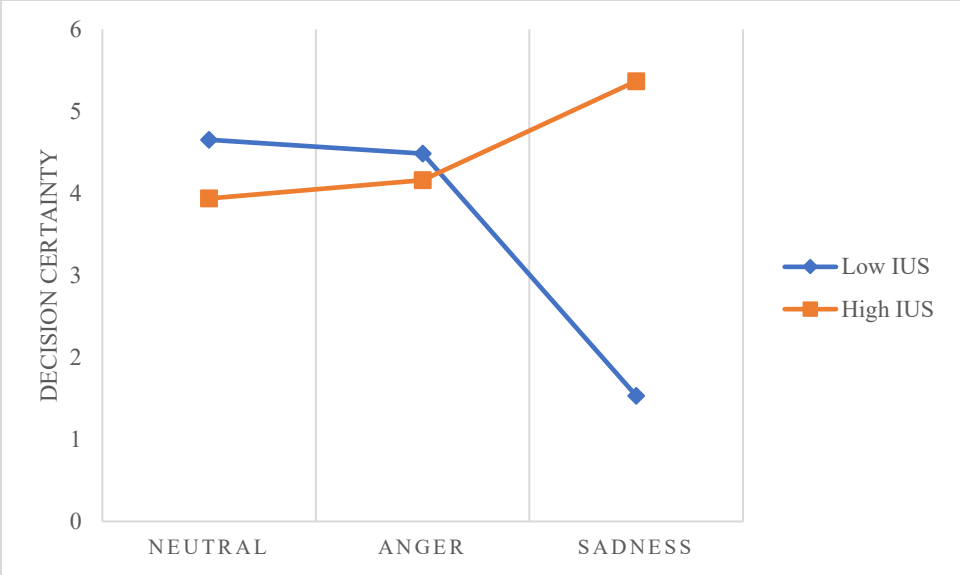


Figure 2. Decision certainty (7-point Likert scale from 1 = 'not at all certain' to 7 = 'extremely certain') by group for low IUS scores (1SD below mean) and high IUS scores (1SD above mean).

Chapter 4: Discussion

Our study examined multiple aspects of the genetic counselor decision-making process when assessing whether counselors refer clients to mental health services. Using elements of the appraisal tendency framework of decision-making, we hypothesized that GC emotional state would influence the certainty of genetic counselor referral decisions. Findings suggest that negative emotion, especially sadness, may affect the referral decision-making process. It also appears that genetic counselors are not aware of the influence of sadness on referral. Additionally, our findings show that when people are sad, IUS is strongly associated with the certainty of their mental health referral. In particular, people who are high in IUS were more certain than those who are low in IUS.

Interaction between emotional state and certainty of decision-making

Mean certainty scores were higher for the anger and sadness groups than control, although this difference was not statistically significant. While only a trend, it is consistent with our hypothesis that anger and sadness would increase certainty of decision-making. Interestingly, sadness appeared to have a significant effect on decision-making whereas anger did not, which contradicts previous literature that shows anger with the largest effect size when using essay-based and other emotion induction methods (Lench et al., 2011). There are several potential explanations for this pattern. Past research has shown that when the framing of a story follows the appraisal pattern of an emotion, it tends to elicit that emotion in the reader (Kuhne & Schemer, 2015). For example, in this study, the case vignettes more strongly followed the appraisal pattern seen in sadness, presenting negative situations that are uncertain, uncontrollable, and not the fault of anyone involved. Reading about these cases might have further elicited sadness in GCs, reinforcing the sadness emotion induction.

This study is the first documented use of the autobiographical essay-writing emotion-induction technique with genetic counselors. It is possible that traits unique to genetic counselors make them more sensitive to sad versus angry emotions. The effect size for this study was based on a meta-analysis of emotion induction studies (N=687), which included 60% females and 87% college students (Lench et al., 2011). Our study population was predominantly female, and all master's level educated. Past research has shown a modifying effect of gender identification on emotional response to experiments. Women tend to be more sensitive to emotion in general, whereas those who identify with a male gender role show more outwardly expressed anger and less anger control (Kopper, 1993; Milovchevich, Howells, Drew, & Day, 2001); however, expressed anger may not directly correlate with experienced anger.

In addition, a review of the contents of the essay writing exercise showed that most individuals in the sadness group (N=13/16) wrote about death or serious illness of someone they

knew. It is possible that the subject matter in these essays had a more salient effect on mood than topics covered by the anger group like politics, workplace conflict, and discrimination. This possibility should be considered with caution, however, as the essay contents were not formally qualitatively analyzed. Lastly, this trend was seen in a small sample size and may have been subject to sampling bias.

Emotional state as a factor of decision-making

Genetic counselor participants did not think their emotional state was one of the most important factors influencing the mental health referral decision. Our findings are suggestive that our hypothesis is true. They are also consistent with past research that shows clinicians are not always aware of emotion's effect on their decision-making (Harun, Finlay, Salek & Piguet, 2015; Tentler, Silberman, Paterniti, Kravitz, & Epstein, 2008). There are several possible explanations for why GCs ranked their emotional state as less important when making a referral decision.

Almost one half (44%) of respondents reported they have not participated in any kind of clinical supervision in their professional career. Although the difference in awareness of emotional state in decision making was not significant between participants who had supervision and those who did not, preliminary data suggest supervision may increase awareness of emotion's role in decision-making. This is consistent with past research that shows supervision and feedback on clinical practice increases emotional awareness, resilience, emotional regulation, and empathetic accuracy in clinicians (Francis & Bulman, 2019; Barone et al., 2005). GCs have long advocated for routine supervision to be more widely incorporated into genetic counseling clinical practice (Kennedy, 2000). More data are needed to confirm whether clinical supervision—which includes learning skills to identify one's emotional state when interacting with clients—could mitigate the influence of a GC's incidental emotion on their clinical decision-making.

It is also possible that, even if GCs were aware of the potential for their emotional state to influence their decision-making that the other referral factors listed in our survey were more important to them. Our list was based on mental health referral decision-factors self-reported by GCs in a 2018 qualitative study (Cunningham et al., 2018). Therefore, these factors might have resonated with counselors more than 'my emotional state,' or seemed more important. There is only one study exploring the influence of GC emotion via countertransference, and it focuses on this topic with respect to GCs guiding client decision-making, but not the influence on GCs themselves (Reeder, McCarthy, Veach, MacFarlane, & LeRoy, 2017). More research is needed to understand how GCs think about the effect of their emotional state specifically on their clinical decision-making.

Decision-making and trait tolerance of uncertainty

Certainty of decision-making was consistent between individuals scoring high or low IUS within the anger and neutral groups, but not in the sadness group. IUS did not have a main effect in the neutral and anger groups. Sadness strongly modified the effect of IUS on decision certainty, such that individuals with low tolerance for uncertainty were more certain in their decision-making, whereas those with high tolerance for uncertainty were less certain of their referral decision. Although we anticipated a potential interaction between IUS and induced sadness, this interaction followed an opposite pattern than expected. Low tolerance for uncertainty (high IUS) in the sadness group was expected to predict lower certainty in decision-making, yet it predicted higher certainty. It is difficult to explain why we saw this interaction based on the literature. Due to the small sample size in our study, it is possible sampling bias due to small sample size played a role in this finding.

Genetic Counselor Clinical Practice

Self-reported GC clinical practice suggests that, although genetic counselors believe it is within their scope of practice to make mental health referrals (85.5%), they are not frequently making referrals. Overall, GCs reported making few referrals, with almost 1/3 of respondents making no mental health referrals in the last year. Based on national averages, we would expect that roughly 20% of patients who GCs encounter experience some form of mental illness. Given that GCs frequently see vulnerable populations such as those in health crises or living with a chronic illness, this number might be higher. If GCs are seeing roughly 550 patients per year, this would mean about 110 patients annually would warrant mental health support. Our data suggests that genetic counselors overall are under-referring clients.

There are several explanations for why GCs are not making more mental health referrals. A subset of respondents reported whether they were discussing mental health generally with their clients. All of these participants reported having mental health support discussions with clients in the last year, and at a higher frequency than which they refer. Therefore, GCs appear to discuss mental health more commonly than they make a referral. As one respondent commented, most clients they see with mental health problems already have an established care relationship with a mental health professional. Since GCs commonly interact with patients suffering from chronic disease and these patients often suffer from mental health co-morbidity, it is a reasonable explanation. Nevertheless, there is little research that directly examines this question.

Past research has outlined barriers to referral in both genetic counseling and other medical professions. One study that interviewed genetic counselors cited both patient-specific barriers (e.g. “patient does not see benefit in referral”) and logistical barriers (e.g. “difficult to identify mental health providers”) to referral (Cunningham et al., 2018). In accordance with this research, one participant in our research commented that there was no avenue in this person’s clinic to make referrals.

Limitations

The greatest limitation to our study was enrollment of study subjects. The sample size of N=55 met less than 15% of our recruitment goal of N=375. As noted in the methods section, half of participants who read the consent stopped the survey after viewing the instruction to write an emotion induction essay suggesting that the exercise was a major barrier to participation. A challenge in future research will be to design methods of emotional induction that would be more acceptable to subjects. More data are needed to determine if the trends seen in our preliminary analysis hold true for a larger sample size. Although this study distributed to over 3,000 GCs, only 55 chose to complete our survey. It is possible that individuals who participated in this study have a particular interest in mental healthcare and do not represent the larger population of GCs.

This study focuses on hypothetical clinical scenarios which could limit generalizability to real-life clinical interactions. In addition, our study only focuses on one aspect of mental health referral by genetic counselors and does not address systematic barriers to referral. It is possible that logistical considerations play a greater role in determining follow through with mental health referral than individual genetic counselor decision-making.

Conclusion

This study focuses on how genetic counselor incidental emotion may influence the decision whether to refer clients to mental health services. Our data do not yet provide sufficient evidence to support our hypothesis that anger and sadness increase certainty of GC referral decision-making according to the ATF model. Our data do suggest that genetic counselors may be unaware of the importance of their emotional state in decision-making. In addition, sadness significantly modified the relationship between IUS and decision certainty. This finding is

inconsistent with previous literature and may be a result of sampling bias. This study provides preliminary evidence that emotion is a factor influencing clinical decision-making for GCs.

Future Directions

This is the first study to evaluate the effect of genetic counselor emotion on referral decision-making. More research is needed to understand why sadness had a greater effect when making clinical evaluations in this setting. Genetic counselors frequently confront and engage with sad topics in their daily practice. Research on real-life clinical interactions will help to establish referral guidelines and increase consistency in referral practices. Incorporation of objective tools may help GCs facilitate referrals in more ambiguous clinical scenarios. Further research is needed to help gain understanding of GC clinical practice and establish practice guidelines that will aid GCs in offering mental health referral when appropriate.

Appendix A: Study Instrument

Consent

You are being asked to participate in a research study conducted as part of a JHU/NHGRI genetic counseling student master's thesis. This study focuses on **referral of patients for mental health treatment**. We are hoping to learn about factors that may affect referrals by genetic counselors.

You are eligible to participate in this study if you are a board-certified genetic counselor with a minimum 1 year of experience, and you currently work directly with patients.

If you decide to participate in the study, it will take **approximately 20 minutes to complete**. As part of this study, **we will ask the following items**:

- Demographic information, including your age, biological sex, and race/ethnicity.
- Information about your clinical practice, such as years practicing as a genetic counselor, current specialty, and mental health referral practices where you currently work.
- Some people may be asked to write a brief description of a personal experience, which will be kept confidential and anonymous.
- You will also be asked to read descriptions of hypothetical genetic counseling cases, similar to what you might see in clinic.
- This survey focuses on mental health and may include topics of an emotional nature.

Those who complete the survey in full will receive a **$10 Amazon gift card** in exchange for their time. You will also have the option to receive a **summary of study results** once they are available (approximately February 2020). We will provide a link to a separate form where you may enter your preferred e-mail address for us to contact you. This information will not be linked to your survey responses. Your e-mail address will only be used for gift card and study data distribution and will not be shared with anyone besides the student investigator. E-mail addresses will be stored on a government encrypted computer and **will be deleted after e-mails are sent out**.

Participation in this survey is completely voluntary. The survey will be given using Qualtrics survey builder and will not collect any personal information. All responses to the survey will be kept anonymous. You may stop the survey and opt out of study participation at any time. **Initiation of the survey will indicate consent to study participation.**

If you have any questions or concerns please contact student investigator Hannah Campbell (hcampb11@jhu.edu) or co-investigator and faculty advisor, William Klein (kleinwm@mail.nih.gov).

Please click on the arrow below if you would like to proceed to the study survey.

Emotion Induction [Randomize subjects to either 'angry', 'sad' or 'neutral control' group]

Angry/Sad Groups: *Please briefly describe 3-5 things that currently make you very [angry/ sad]. Please describe in more detail the one recent situation that has made you most [angry/ sad]. Write your description in such a way that someone reading it might even become [angry/ sad] just from learning about the situation. You should write for about five minutes.*

We appreciate you taking the time to complete this writing exercise as part of the experiment. The contents of your essay will be kept confidential and anonymous.

Neutral Control Group: *Please briefly describe 3-5 rooms in your house. Please describe in more detail one room in your house. Write your description in such a way that someone reading it might even be able to imagine themselves in that room. You should write for about five minutes.*

We appreciate you taking the time to complete this writing exercise as part of the experiment. The contents of your essay will be kept confidential and anonymous.

Induction Validation (¼ of participants from each of the three experimental groups randomized to complete the PANAS questionnaire)

Positive and negative affect schedule (PANAS) (Watson, Clark and Tellegen, 1988)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you feel this way right now, that is, at the present moment. Use the following scale to record your answers:

1	2	3	4	5
Very slightly	a little	moderately	quite a bit	extremely

___Interested
___Distressed
___Excited
___Upset
___Strong
___Guilty
___Scared
___Hostile
___Sad
___Enthusiastic
___Proud
___Irritable
___Alert
___Ashamed

___Inspired
___Nervous
___Angry
___Determined
___Attentive
___Jittery
___Active
___Afraid

Case Vignettes

Vignette #1: *Carol and her 9 y.o. son, Aiden, are referred to you for follow up and genetic counseling related to Charcot-Marie-Tooth (CMT) hereditary neuropathy. Aiden's father also has CMT but is estranged from Carol. Aiden was diagnosed clinically when he was 6 years old and started 'walking differently'. His condition is stable, and he is expected to have good mobility as an adult. Aiden is able to participate in sports and other physical activities with only mild fatigue. As you explain genetic testing options to Carol, she speaks very quickly and has lots of questions. You explain to Carol that genetic testing would mostly help ensure that Aiden qualifies for assistance in school if he needs it. Carol expresses concern that Aiden will be treated as 'different' if he gets assistance. You ask Carol how Aiden has been getting along with his peers, and she says he has lots of friends. Aiden says that his friends know about his CMT and let him take a break when he gets tired. He also has friends who get special help in school and no one minds. Carol says that even though she knows Aiden is happy, she continually worries about him being rejected by his peers, and his condition getting worse.*

Vignette #2: *Jordan is referred to you for genetic counseling related to a personal history of breast cancer at age 60, and to discuss the risk for HBOC in her family. Jordan has been in remission for three years after receiving treatment for her breast cancer. As you are talking, you notice Jordan's eyes are directed downwards, she continually shifts in her seat, and she seems distracted. You review Jordan's family history and assess that she meets criteria for genetic testing. You order a broad cancer panel, which comes back negative for pathogenic variants. You call to disclose the results to Jordan and she expresses understanding. She explains that ever since she was diagnosed with breast cancer, she has worried about a recurrence. She was hoping genetic testing would make her worry less, but says she still feels like her cancer is going to come back.*

Vignette #3: *Daryl is a 25 y.o. male referred to you for genetic counseling related to a genetically confirmed diagnosis of Marfan syndrome. It is believed that Daryl inherited the condition from his mother, who died of an aortic dissection when he was an infant. Daryl is new to your clinic after moving to the area a year ago. His condition is mild, and he was first diagnosed as a teenager. Since then, he has had annual visits with genetics to check in and screen for heart complications. Before seeing you, he has an echocardiogram, which is normal. Throughout the session, he speaks very little and appears tired. You ask about his exercise habits, and he says he walks a little, but doesn't exercise much. You discuss ways Daryl can safely engage in physical*

activity. After further questioning you find out that Daryl used to play football in high school but was told by his doctor to stop playing after his Marfan diagnosis. He says most of his friends were on the team and stopped hanging out with him when he quit. You ask what kinds of social activities he participates in now, and he says he doesn't know. When you ask whether his friends know that he has Marfan syndrome, he says he doesn't talk to them about personal stuff.

Case Assessment (after each vignette)

Quantitative Assessment

1. [Carol (the mother)/Jordan/Daryl] has depressive symptoms

Not at all 1 2 3 4 5 6 7 A great deal

2. [Carol/Jordan/Daryl] has symptoms of anxiety

Not at all 1 2 3 4 5 6 7 A great deal

3. [Carol/Jordan/Daryl] is in distress

Not at all 1 2 3 4 5 6 7 A great deal

4. How likely would you be to offer to follow up by phone or in person with [Carol/Jordan/Daryl] to continue this conversation and gather more information about [his/her] mental health (assume time is not a factor)

Not at all likely 1 2 3 4 5 6 7 Extremely Likely

5. I would refer [Carol/Jordan/Daryl] to a mental health professional

Yes

No

6. Referring to the previous question, how certain are you of this answer?

Not at all certain 1 2 3 4 5 6 7 Extremely certain

Referral Decision Factors

Please rank which of the following factors influenced your decision to refer/not refer [Carol/Jordan/Daryl] with 1= most important to 9=least important [drop down options: 1-9]

__Reason patient presented to genetics services
__[Patient/Mother] distress level
__My emotional state
__Patient's family history
__[Patient/Mother] reminds me of someone I know
__Time since patient's diagnosis
__[Patient's/Mother's] engagement in session
__[Patient's/Mother's] social support

__[Patient's/Mother's] reaction to genetic diagnosis

Demographics

Age: [Enter value]

Biological Sex: [Select one]
- Male
- Female
- Other
- Choose Not to Specify

Race/Ethnicity [Select all that apply]
- White
- Black/African American
- Native American/Alaska Native
- Asian/Pacific Islander
- Hispanic/Latino
- Other

In what genetic counseling setting do you currently work? [select all that apply]

Prenatal
Cancer
Pediatrics
Research
Laboratory
Other [please specify]

For how many years have you been a practicing genetic counselor? [Enter value]

For how many years have you worked in your current setting? [Enter value]

Some masters' degree programs ask students to regularly meet one-on-one with a faculty member to discuss and process cases. Was this type of clinical supervision included in your masters' degree program?
- Yes
- No

As part of your professional career, which of the following have you participated in [select all that apply]?
- One-on-one supervision with a colleague/mentor
- Peer supervision group
- I have not participated in clinical supervision

How many patients, on average, do you see per week? [Enter value]

Approximately how many mental health referrals have you made in the last 12 months?
None
1-5
6-10
11-15
>15

I routinely screen patients for mental health concerns (either by discussion or a formal method).

Yes

No

If yes, I use a screening tool to help with my assessment.

Yes

No

There is a formal system in place for me to make a mental health referral in the clinic where I currently work.

Yes

No

There is a full-time mental health specialist on staff in the clinic where I currently work.

Yes

No

It is within my scope of practice to refer a patient to mental health services.

Yes
No

[Optional] If there are any comments that you would like to provide, or anything that we haven't addressed in this survey, please write here. [text box]

Intolerance for Uncertainty Scale Short Form (IUS-12) (Carleton, Norton, & Asmundson, 2007)

	Not at all characteri-stic of me	A little chara-cteristic of me	Somewhat character-istic of me	Very chara-cteristic of me	Entirely characteristic of me
1. Unforeseen events upset me greatly.	1	2	3	4	5
2. It frustrates me not having all the information I need.	1	2	3	4	5
3. Uncertainty keeps me from living a full life.	1	2	3	4	5
4. One should always look ahead so as to avoid surprises.	1	2	3	4	5
5. A small unforeseen event can spoil everything, even with the best of planning.	1	2	3	4	5
6. When it's time to act, uncertainty paralyses me.	1	2	3	4	5
7. When I am uncertain I can't function very well.	1	2	3	4	5
8. I always want to know what the future has in store for me.	1	2	3	4	5
9. I can't stand being taken by surprise.	1	2	3	4	5
10. The smallest doubt can stop me from acting.	1	2	3	4	5

11. I should be able to organize everything in advance.	1	2	3	4	5
12. I must get away from all uncertain situations.	1	2	3	4	5

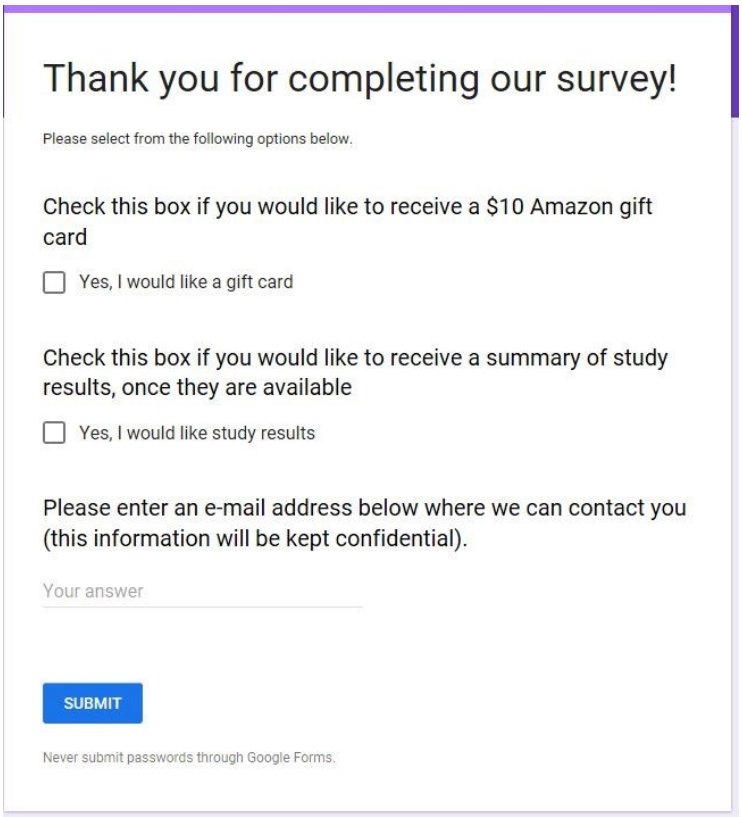
Score: _____

Study Completion

Thank you for taking the time to complete our survey!

If you would like to **redeem a $10 Amazon gift card** in exchange for your time or are interested in receiving **a summary of the results** of this study once they become available, please click on the following link and provide your email address [insert link to Google Form]. **Your contact information will not be linked to your survey responses.**

Google Form (redirected from Qualtrics)



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Biographical Statement

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